

Impact

Feature Issue on Behavior Support
for Crisis Prevention and Response

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Through bringing together the mental health, developmental disability, health care, social service, and criminal justice systems, the Pueblo DD/MH Consortium assists Patrick and others to find productive roles as citizens and contributors in their communities. See story on page 24.

A Crisis is Not an Excuse

by Michael W. Smull

Most crises requiring behavioral support and system response for an individual with a developmental disability can be anticipated. They should not come as a surprise. Those who present complex behavioral “problems” are people who are usually already known – often well-known – to the system. Those who receive services and complain with their behavior about those services, are typically familiar to those who oversee and manage the services. It is often the case that when the individuals first came to the attention of the system they were not listened to, and instead efforts were made to have them comply with the rules of the agencies, programs or residential settings. The efforts did not work. As the individuals escalated their “complaints” about the services and circumstances, there was typically an escalation in the interventions, leading to people being “discharged” and becoming a “crisis.” They were moved to new settings or service providers, and the cycle began again.

For most of the people with developmental disabilities in this situation, there is time for careful planning, for reflection. Part of the reason that the planning does not occur is that we’ve created a culture of chronic crisis. The officials who make decisions about where people live are typically told of someone who needs a new place to live with little lead-time because an agency has decided to “discharge” them, a psychiatric hospital has someone who should not be admitted, or an aging parent has been hospitalized. In these circumstances, the person needs a place to sleep that night. Looking

[Smull, continued on page 26]

From the Editors

For decades public institutions and other segregated settings have served as places of last resort for persons whose behavior, emotions or crisis circumstances presented challenges beyond the capacity or commitment of community service agencies. One of the last frontiers in the movement to assure a life in the community for all people with intellectual and developmental disabilities is the development of behavior support and crisis prevention and response programs in the community. These programs provide people experiencing behavioral, emotional or other crises – and the families and organizations that care about them – with immediate and ongoing support and treatment that allow them to remain in the community. Among programs emerging from communities committed to retaining each of their members are comprehensive state and regional programs serving areas in which institutions no longer exist, interactive video consultation services that reach people across large distances, and diversion programs for persons involved with the criminal justice system. All share a commitment to positive behavior supports, multidisciplinary services, and the philosophy that personal crisis is an unacceptable excuse for institutionalizing people. It’s that commitment which is described in this issue of Impact.

What’s Inside

Overview Articles
Program Profiles
Additional Resources



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Community for All: Experiences in Behavior Support and Crisis Response

by K. Charlie Lakin

During the last three decades the U.S. has witnessed remarkable achievements in reducing the number of persons with intellectual and related developmental disabilities (MR/DD) residing in public institutions (Prouty & Lakin, 2000):

- Between June 1967 and June 1999 the number of persons with MR/DD residing in both state MR/DD and psychiatric institutions was reduced by 78% from 228,500 persons to 50,067.
- When deinstitutionalization was just beginning in 1969, the Master Facil-

- Ten states have effectively closed all state MR/DD institutions.

The most visible product of the deinstitutionalization movement in the U.S. has been the depopulation of institutions, but the most important accomplishment has been the concurrent transfer of the full range of services once available only in institutions to the communities in which people are born and prefer to live. Today the vast majority of service recipients and over two-thirds (72%) of service expenditures are in the community (Braddock et al., 2000). Most people with MR/DD who receive services today do so without ever experiencing a day of institutionalization. Indeed, it is statistically demonstrable that the primary factor in the massive depopulation of state institutions has not been the number of people discharged from state institutions, but has been the reduction in the number of people who entered state institutions. Between 1970 and 1998, annual admissions to state MR/DD institutions decreased 84% (Prouty & Lakin, 2000).

There has been a well-researched association between movement from institutional settings to community living and the acquisition of functional skills. This research makes a very strong case for community living as a powerful, albeit loosely defined, treatment model for adaptive behavior skill growth (Kim, Larson & Lakin, 1999). Studies of the association between community placement and changes in “challenging” behavior have shown much less evidence of statistical association between community placement and lower rates of challenging behavior.

The review by Kim, Larson and Lakin (1999) identified six “comparison group” studies between 1980 and 1999 that directly compared challenging behavior changes over time among per-

sons deinstitutionalized and matched groups of people remaining in institutions and another 18 “longitudinal studies” which monitored change over time in the challenging behavior of people who moved from institutions to community settings. These studies followed thousands of subjects over periods ranging from 6 months to 84 months. Only one of these comparison group studies and five of the longitudinal studies showed statistically significant relative decreases in problem behavior among like persons moving to the community. Ten of the remaining studies showed non-significant tendencies for improved behavioral outcomes associated with community living, but six showed tendencies toward negative outcomes in behavior, and two even showed statistically significant worsening of problem behavior following movement to the community. In short, community living is not, in and of itself, an effective method for meeting the behavior support and/or crisis prevention and response needs of individuals with MR/DD.

A number of factors may be hypothesized to contribute to the lower consistency of association between “maladaptive” behavior change and movement from institutions than has been found between positive “adaptive” behavior change and movement into community settings. These range from community life being a more direct and consistent teacher of the functional skills assessed as “adaptive behavior” to the complications of psychiatric conditions in reducing “maladaptive behavior.” Whatever the explanations, it appears that community living alone is insufficient as a vehicle of behavior support and training to prevent and respond to challenging behavior. But, more importantly, the evidence is clear that institutionalization for the purposes of developing adaptive behavior

Community living is not, in and of itself, an effective method for addressing behavior support and/or crisis prevention and response needs of people with MR/DD.

ity Inventory of the United States showed only 10,350 people with MR/DD living in community residential settings of 15 or fewer residents; by 1999, 278,450 people with MR/DD lived in community settings.

- As a result of state commitments to provide community services to all who can benefit and to eliminate unjustifiably costly services, in the 12 years between 1988 and 1999, 116 state MR/DD institutions and MR/DD units of 16 or more residents within traditional psychiatric institutions were closed.
- Including the 33 state institution closures before 1988, by 1999 only 56% of all state institutions operating in or established after 1960 remained in operation.

and/or reducing maladaptive behavior offers no dependable (i.e., defensible) treatment benefit.

The *Olmstead* Decision

Most states have made substantial progress toward assuring community lives for all citizens with MR/DD, but others have much more to do. Today, the primary predictor of people's access to opportunities and services that can support them as needed in the communities in which they live is the state and community in which they happen to reside. This relative fortune or misfortune and the essential injustice it may represent was a primary motivation of the landmark *Olmstead* suit.

Arguing that restrictions that derive from government's unwillingness to respond to established benefits of community life, as identified and assured by Congress in the Americans with Disabilities Act (ADA), constituted unlawful discrimination, two individuals in Georgia used the civil rights protections under the ADA to pursue their place in the community. In June, 1999, the Supreme Court of the United States issued a ruling in *Olmsted et al. vs. L.C. et al.* of great significance to persons with MR/DD who are or might be institutionalized as a result of behavioral and/or psychiatric service needs.

In the ADA, Congress noted that the isolation and segregation of individuals with disabilities represented a "serious and pervasive social problem" because it was a form of discrimination (42 U.S.C.12101[a][2]), and that such discrimination was reflected in "outright intentional exclusion" and "relegation to lesser services, programs, activities, benefits, jobs, or other opportunities" (42 U.S.C. 12101[a][5]). Congress noted that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, economic self-sufficiency for such individuals" (42 U.S.C. 12101[a][8]).

The federal regulations, responding to the intent of Congress, required that

a "public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified persons with disabilities" (28C.F.R.35.130(d)). The Supreme Court in *Olmstead* considered specifically whether it was a violation of the ADA for a state to deny individuals community placement when community services were available to others, when community services were recommended for the individuals by the state's professionals, and when community services were desired by the individuals.

The majority opinion of the Court concluded that:

The ADA both requires all public entities to refrain from discrimination and specifically identifies unjustified segregation of persons with disabilities as a form of discrimination. The identification of unjustified segregation as discrimination reflects two evident judgements. Institutional placement of persons who can handle and benefit from community setting perpetuates unwarranted assumptions that persons so isolated are incapable and unworthy of participating in community life...and institutional confinement severely diminishes individuals' everyday life activities.

The significance of the *Olmstead* ruling is yet to be determined. It is likely to be most influential in states that have made the least progress in deinstitutionalization, but its implications are by no means limited to such states. It will contribute to the ongoing push to reduce institutionalization and to challenge communities to serve people who in the past have been viewed as appropriately housed in institutions.

A January, 2000, letter to State Medicaid Directors from the Departments of Health and Human Services and Justice in reference to the *Olmstead* decision noted that:

This decision confirms what this Administration already believes: that no one should have to live in an institu-

tion or nursing home if they can live in the community with the right support and that *Olmstead* challenges states to prevent and correct inappropriate institutionalization and to review intake and admission processes to assure that people with disabilities are served in the most integrated setting appropriate.

Relevance of *Olmstead* to Behavior Support/Crisis Response Programs

The fact the petitioners in *Olmstead* were persons with histories of behavioral and psychiatric diagnoses and treatment is significant. In June 1998, 165 state institutions (84.2% of 197 total) reported that 41.4% of their residents had behavior disorders requiring special staffing and 34.3% had psychiatric conditions requiring the involvement of professionals with psychiatric training. *Olmstead* suggests that continued reliance on institutional settings as a primary locus for specialized services for people who present behavioral challenges to community service systems will be under growing pressure. This pressure may be important. During the 1990s as state institution populations decreased 41% nationally, in the one-third of states with the slowest rates of deinstitutionalization institution populations decreased by 23%. Fifty-seven percent of all state institution residents were in that slowest one-third of states.

Continuing the designation of public or other types of institutions as "specialized" places for treating people with behavioral and psychiatric disabilities in light of the lack of demonstrated benefit to their problem behavior and the well-demonstrated detriments to their functional skill development – and now the *Olmstead* ruling – seems substantially threatened. *Olmstead* further suggests that traditional uses of larger institutions as the "safety net" for emergencies and crisis will be susceptible to challenges as less segregating community alternatives are designed and demonstrated to be effective.

[Lakin, continued on page 27]

Meeting the Challenge: Crisis Services in the Community

by Ronald H. Hanson and Norman A. Wieseler

The deinstitutionalization of persons with intellectual disabilities or related conditions has produced dramatic changes in their lives. This is especially true for persons with challenging behavior, such as aggression toward others, self-injury, property destruction, public disrobing, sexual predation, and other behaviors previously managed within institutions. Behavior training programs and psychotropic medications have been the primary strategies for reducing the frequency and intensity of such challenging behaviors among individuals now living in the community. To sustain community living, specialized services are required. These crisis prevention and response services must include professionals with expertise in treatment of challenging behaviors utilizing positive behavior intervention and support.

For some individuals living in the community, psychiatric hospitalization has been the only treatment option available for behavior support or crisis response. But, it has come at a high cost, often proving to be disruptive and problematic for the individual, their family, and for the staff of the community residence and the psychiatric hospital unit. The hospitalized person with developmental disabilities can be vulnerable to exploitation by higher functioning psychiatric patients and must be closely supervised by hospital personnel. Hospital staff often have limited experience working with individuals with intellectual disabilities, and in some cases have requested that direct service providers remain at the hospital to care for the person. While such extra staffing may enhance care, it often reduces support for others living in the individual's home.

Individuals with a mental health problem in addition to their developmental disability are frequently difficult to serve because they can "fall between the cracks" of services in the health care

system. The system is usually organized to serve either the individuals with mental illness who have average intellectual abilities, or alternatively, individuals with intellectual disabilities who are well adjusted and do not evidence an emotional or psychological disturbance. Because of the concurrent mental health disorders often observed in this population, crisis services are often needed for individuals who range in age from childhood to those in advanced years of adulthood.

Key Features of Community Support

People with mental health disorders and developmental disabilities often benefit from a range of approaches, including the following:

- **Psychotropic Medications.** Psychotropic medication can be a beneficial adjunct to positive behavioral intervention. In the past 10 years, effective medications, specifically the atypical antipsychotics and the selective serotonin reuptake inhibitor antidepressants, have become available. For individuals with psychosis, depression, or other mental health disorders, the use of psychotropic medications in combination with positive behavior intervention and support procedures has been effective in the prevention of crisis occurrences. However, monitoring of the appropriateness and effectiveness of these and other medications on an ongoing basis must be part of any intervention using psychotropic medications.
- **Supervision and Structure.** In addition to the use of medication, vigilant supervision by care providers is necessary to ensure that individuals with challenging behaviors do not place themselves or others at risk. This means it is necessary to have

funding for and access to residential and other settings with appropriate levels of staffing. In such settings, structure, through the daily scheduling of activities and tasks, is also an essential component in crisis prevention. This includes arranging the environment so positive behavior supports will reward both independence and prosocial alternative responses to challenging behaviors. An example of this structure building is through the scheduling of 15-minute increments of activities in which the individual will be involved during the day and evening hours until bedtime. The events may vary based on available opportunities and individual choice, but the creation of and adherence to the schedule is consistent.

- **Staff Consistency.** The therapeutic goals in responding to challenging behavior depend on direct service providers following specific training approaches and responding to the individual in a respectful and systematic manner. This is often referred to by treatment staff as the "consistency of program implementation." Differences in both the expectation and the interaction with the individual among staff members create a more difficult learning environment. Without staff consistency, there will be varied staff responses to the person's positive or challenging behaviors, and differing staff expectations concerning the individual's level of independence. Inconsistent responding by direct service providers is often a setting event for challenging behaviors and can make the crisis situation even more serious. To achieve consistency, behavior support and crisis response service staff must work diligently to increase communication among all care providers. They must

also assure that detailed, written treatment plans are developed and carefully taught to those expected to implement the specific practices.

The many factors contributing to difficulties in recruiting, training, and retaining direct support staff have made the challenge of providing consistent staff response more difficult. High staff turnover, positions remaining unfilled due to the limited numbers and qualifications of interested candidates, and use of staff from temporary agencies all make establishing consistency a higher hurdle. Additionally, increasing numbers of direct support staff have no training or experience in participating in systematic analysis of behavior or implementation of behavior supports. As a result, highly specific training with frequent observation and ongoing support of staff are increasingly important for consistent and effective treatment.

System Planning

When developing behavior support and crisis response services, system planning must ensure that services will be comprehensive and coordinated. This may begin with agencies or local governments developing services individually or collaborating with other agencies or governments to provide services regionally. In rural areas, agencies and local governments may form regional cooperatives to develop and oversee crisis services. State agencies are an important part of crisis service programs because of funding and regulatory requirements. But in many instances, state involvement may extend to service delivery, as well. State employees who have had extensive previous experience with individuals with challenging behavior while they were living in state institutions can be an important component of state involvement in providing community behavior support and crisis services. Private contractors can also be hired by state and local government or private authorities to provide core behavior sup-

port and crisis intervention services.

An important design feature for crisis prevention and response is the provision of services where the individuals actually live and work. Thus, in practice, behavior analysts, nurses, and other behavior support and crisis service personnel travel to settings where the person's challenging behaviors actually occur. Staff visit the residence, day program, employment, or school setting to observe the interaction between the individual with challenging behaviors and others in his or her environment. This naturalistic observation differs from the traditional office-based counselor-client psychotherapeutic approach. This orientation requires mobility of the crisis service staff member and the capability of being in numerous settings each work day. Anticipation of transportation needs and costs for the mobile workforce must be considered during development of crisis services. Using modern technology such as laptop computers to quickly generate treatment reports from the field or cell phones to keep in touch on the road also ensures responsiveness and timely assistance to the referring agency and other team members.

Knowledgeable behavior analysts are, of course, the essential ingredient in successful behavior support and crisis response services. The most effective are those who have the maturity, experience, and communication skills to advise a diverse range of direct service providers in a sensitive and credible manner. Usually this implies a well-trained behavior analyst with excellent skills in functional assessment and positive behavior support, who has at least two or more years of experience in program development in residential, vocational, and school or day treatment settings. An extensive knowledge of mental health, developmental disability, and other relevant community resources in their region is also a very helpful.

The collaborative relationships among crisis response staff, psychologists, psychiatrists, and psychiatric nurses are important. The psychologist brings skills in intellectual and behav-

ioral assessments as well as providing insights regarding the dynamics of the living and working situations. The psychiatrist can provide skill in medication management and may recognize physical conditions contributing to behavioral disturbances. Broad case consultation among behavior analysts, psychologists, psychiatrists, psychiatric nurses, and when necessary, individuals from other disciplines (e.g., speech therapy, dietetics, physical therapy, occupational therapy, clinical pharmacy, and other related specialties) provides a broad foundation on which to make treatment decisions.

Summary

The systematic and comprehensive provision of crisis prevention and response services allows many people with developmental disabilities, severe challenging behavior, and/or mental health disorders to remain stable members of the community. The delivery of behavior support and crisis services in the community benefits the individual, their residential settings, and the social service system by enhancing the person's independence and self-determination, and avoiding costly and disruptive psychiatric hospitalizations.

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Functional Assessment: Responding to Challenging Behavior

by Rachel Lynn Freeman and Christopher I. Smith

Effective support and treatment of people who exhibit challenging behavior in their daily lives depends on being able to understand the “function” that the behavior serves for the individual. Often, behavior that might be seen as maladaptive or crisis-causing makes sense within the context of a particular person’s life (i.e., gets them what they want and away from what they don’t want).

Functional assessment identifies the variables that predict and maintain problem behavior, and is used to improve the effectiveness and efficiency of behavioral support plans. This information can be especially important when trying to support a person whose behavior has become so intense that it has resulted in health or safety concerns. The functional assessment process assists in building behavioral support plans that are technically sound in their application of behavioral principles.

Components and Considerations

In functional assessment, there are three components – indirect assessment, direct assessment, and functional analysis – and two related considerations – contextual fit and systems-level assessment:

- **Indirect Assessment:** Indirect assessment includes interviews, written records, checklists, and questionnaires. Interviews with key people who are familiar with an individual’s problem behavior can help to narrow the range of variables influencing the behavior. These individuals may include people who are present when problem behavior occurs, or those who know the person well, as well as the individual engaging in problem behavior (depending upon communication skills and interest level). A review of records can provide information on past history, while quality of life measures may indicate other

aspects of the individual’s life that can be addressed as part of a behavior support plan. Finally, checklists and rating scales are available that provide insight into the function of the individual’s problem behavior or the factors that may predict it.

- **Direct Assessment:** Direct methods of assessment involve observing the individual to identify when problem behavior occurs, what happens right before problem behavior, what problem behavior looks like, and how people respond to the occurrence of problem behavior. Direct measurement methods document the frequency, duration, latency, and intensity of problem behavior. Narrative data can help identify and confirm the immediate events in the environment that precede and follow the occurrence of problem behavior. A descriptive method of data collection will often involve documentation of identified setting events, antecedents, and maintaining consequences.
- **Functional Analysis:** A functional analysis tests hypotheses about a challenging behavior by systematically manipulating the variables or events that are thought to be associated with the occurrence of problem behavior. It is a formal test of the relationship between environmental variables and the occurrence (and non-occurrence) of behaviors. Researchers use this approach because it is the most controlled method for demonstrating the functional relationship between environmental events and challenging behavior.
- **Contextual Fit:** It is critical to attend to variables that will increase the “contextual fit” between an individual’s behavior support plan and those who will implement the plan. One reason for the failure of behav-

ior support plans may be related to the lack of attention to how well a behavioral support plan matches the values, skills, and resources within the social network that will be implementing the plan. A behavior support plan with good contextual fit will: a) include interventions that work well in the target environment, b) identify extra training for staff when needed, and c) seek out resources available for behavioral support plan development.

- **Systems-Level Assessment:** An often overlooked but important task in positive behavioral support is to gather information that considers issues related to contextual fit by conducting a systems-level assessment. A systems-level assessment looks at resource availability, staff development processes, and the values of the individuals involved. Failure to consider the systemic issues related to resource availability and the characteristics of individuals involved may result in inconsistent implementation or complete rejection of the behavioral support plan.

Functional Assessment in Support

Functional assessment methods can be used to support persons with developmental disabilities in at least two important ways: developing behavior support plans that can be used in a variety of home and community settings, as well as ongoing assessment and adaptation of the plan and its goals.

Once an implementation team has decided upon the design of the behavioral support plan, the implementation process begins including any training needed to ensure successful implementation. It is important to consider longitudinal strategies that document the

training process, so that any new members of the individual's social network can be given similar training. Ongoing data collection systems for the behavior support plan must be established, and access to resources needed for the behavioral support plan are put in place during the support plan implementation process. Administrative changes that might ensure successful implementation are also created. An example might be an administrative system that ensures that staff are free to attend regular team meetings, review the behavioral and other data, make modifications to the plan, and embed the behavioral support plan training into larger staff development systems within an agency.

Neither challenging behavior, nor the broader social and service system within which it occurs, remains static. Behavior often changes radically, the people in an individual's social network may change, or the individual may move to a different home or community. This means that functional assessment is an ongoing process, not a one-time event. Functional and systems-level assessments allow us to continually improve the behavioral support plan and assess resources that are needed to maintain quality of life for the individual.

Staff and Systems Issues

The building of collaborative teams and the assessment of systems-level factors affecting provision of services are two essential steps in the process of building community capacity to provide positive behavioral supports that draw upon a functional assessment approach.

Fostering a collaborative team process in positive behavioral support traditionally has not received much attention. The ability to work together effectively in interdisciplinary teams, however, is considered a crucial skill. The level of awareness an implementation team has about its own strengths and areas of need related to positive behavioral support can create opportunities for dialogue and problem solving during the design and implementation process.

Important variables related to the implementation team include the skill level and experience of the individuals involved, the values and beliefs held by family and support providers, and the stressors that affect each team member.

Systems-level factors related to the larger environmental issues within an agency also need to be addressed in terms of the role they play in challenging behaviors. Attention may need to be given to a) assessment of the entire social network, b) management and resource-related issues, and c) staff development systems. Variables within the environment that influence the likelihood of problem behavior are the physical characteristics of the environment, the number of people in the environment and how they interact, and curricular or training activities. An understanding of how these individual environmental variables influence behavior can be enhanced when they are observed as existing within a larger social network or system. Observing patterns of social interaction across staff and the individuals they support may provide information overlooked when considering assessment data related to only one individual and the environmental determinants of his or her behavior. Finally, assessing an agency's staff development system will help to ensure smooth behavioral support plan implementation. Being aware of the agency-wide training systems that already exist for staff members may assist the implementation team as they consider training and support needs during plan implementation.

Implementation During a Crisis

Ideally, a functional assessment is conducted before an individual's problem behaviors escalate to a point where the health and safety of the individual or those within the social network are threatened. When this is not possible, the methods used to conduct a functional assessment should be carefully considered when problem behavior escalates to dangerous levels. Implementing a combination of indirect assess-

ment methods, direct observations, and functional analysis contributes to a strong functional assessment.

When an individual has been moved to a more restrictive setting during a crisis situation, information will be needed to develop a clear transition plan outlining the resources and steps necessary to ensure a systematic and predictable return to the individual's home and community. Systems-level assessment issues become crucial during transition planning to address transition needs and positive behavioral support planning. Often, preparation for transition planning can be facilitated by an implementation team member interviewing key staff about transportation issues, schedule processes that will be needed, or temporary resources that may be necessary for the transition plan to occur.

Summary

When a team of individuals is working with a person who demonstrates challenging behavior, functional assessment can help to establish the function of the behavior, as well as the antecedent conditions and consequences that maintain it. Systems assessments can help these teams to be aware of the larger issues that can affect the implementation of behavior support plans such as agency and family resources, team skills and values, and the needs of the team regarding training for implementation of the behavior support plan. Together, these two assessments can increase the effectiveness and efficiency of behavior support plans, and ensure that these plans fit the context within which they are to be implemented. And ultimately these assessments can increase the likelihood of successfully supporting persons in their homes and communities.

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Training and Technical Assistance Strategies for Behavior Support and Crisis Response

by Dan Baker

“Teach us how to hold them down!” Any person helping out with behavioral crises has heard this plea from care providers. When people see themselves as being at physical risk, it is not surprising that the first thing they want to know is how to restrain someone. However, behavior specialists, consultants, and crisis workers should present physical intervention and restraint as a last resort, instead emphasizing proactive supports and prevention. Reactive strategies may be necessary, but should never be the primary component of behavior crisis prevention and intervention.

A behavioral crisis is a situation in which a person is engaging in behaviors which: (a) threaten the health and safety of the individual or others, or (b) may result in the person losing his or her home, job, or access to the community. Behavioral crises are among the greatest challenges faced in supporting individuals with developmental disabilities. Ideally, all support agencies and care providers would be able to respond effectively to any level of crisis. In reality, though, agencies, families, and other support providers often face major challenges, and call in behavior specialists, clinicians or consultants to provide extra assistance and ideas.

Consultants or behavior specialists are likely to provide services that come in the form of either technical assistance or training. The goal of technical assistance or training is to assist the care providers to respond to behavioral crisis in a safe and effective manner and prevent future crises.

Steps in Technical Assistance

In technical assistance situations, the consultant provides more direct assistance and produces products designed to result in the immediate adoption of different interventions and support

strategies, with specific behavior support recommendations. The consultant takes direct responsibility for certain, pre-specified outcomes, such as conducting a functional assessment or writing a behavior support plan. Another consultation design is a “non-directive consultation model.” In this model, rather than providing answers and directly generating materials and plans, the technical assistance provider presents general information and guides local persons through the process of decision-making and intervention design. Additional training is given as dictated by the situation and the type of problems being presented.

There are a number of services that a consultant might provide in delivering technical assistance. The first step is to help in defining the problem. People involved in a crisis often are not able to accurately define the crisis. They may know that a severe problem exists, but may have difficulties describing it. A second type of service that a consultant might provide is to help regular support team members identify why the problem exists. The most common way to identify reasons for problem behaviors is to complete a functional assessment, a process for identifying the things that cause and maintain a problem behavior. Third, a consultant can assist in the development of a behavior support plan, especially a comprehensive behavior support plan. In short, a behavior support plan represents steps in preventing and responding to problems or crises and improving behavior support strategies. Fourth, a consultant can train and support people who are to implement the plan, whether family members, support staff, or other types of care providers. Training for care providers and raising skill levels are among the most crucial of elements in supporting and resolving crises, and can be a key to pre-

venting future crises. Fifth, a consultant can train, counsel, and support the person presenting the problem behavior. This may be time-intensive and is often prohibitively expensive. Sixth, and finally, a consultant familiar with resources in the community can assist with the identification of relevant support services, such as drug and alcohol programs, therapists, psychiatric services, and respite for care providers.

In most successful technical assistance efforts, the technical assistance person and the care providers have a collaborative, ongoing relationship with well-defined roles. Close attention is paid to follow-up and evaluation. Cultivation of this relationship is often a top priority throughout technical assistance efforts. Many actions can build this relationship, such as including care providers in planning and decision making, asking care provider opinions, and getting to know the care providers at least a little. A friendly, non-judgmental demeanor is of great assistance as well.

Training for Care Providers

In training situations, the trainer will provide assistance by raising the knowledge and skill level of care providers. Common training methods include lectures, workshops, demonstrations, mentoring, coaching, or media presentations. Training for care providers often is a significant component of any behavior support effort, and for long-term benefits it is important that some training of care providers occurs in the context of technical assistance provision.

Successful trainers will address the care provider question, “Why do I need to know this?” and explain at the start how the training will help with the behavioral crisis. The best training is “just in time,” as knowledge is best retained when it is put to use immediately. The

longer the delay between learning and use, the less effective the training will be. This is rarely an issue in crisis response, but must be addressed in prevention.

It is also important to build on existing knowledge and relate the new information in a meaningful way to the learners' previous experiences. For example, care providers may have never considered the importance of providing choices to people with disabilities. But they can certainly relate to their own experiences of having or not having control in their jobs or homes.

Trainers should train within or simulate the work environment whenever possible. Care providers will be able to perform best on the job or in their homes when training conditions closely match the environment in which they will be using the skills. For example, if people typically need to tolerate distractions while running a behavior support program (e.g., designing a picture schedule), they will need to practice the skill a few times in situations that resemble those conditions.

Care providers are probably nervous and anxious about what to do in crisis situations and all the new things they need to learn. They may be afraid of injury, investigations, failure, embarrassment, or of not being adequately "gifted" to provide behavior support or handle a tough challenge. If they are frightened or nervous, they are not in a good "learning state." People learn best when they feel comfortable and safe. Trainers must consider what they can do to reduce the fear factor regarding the crisis and increase the confidence level of the trainees. A key component of the learning environment is created by language used in training. Technical jargon often is incomprehensible to care providers, and its use should be minimized.

It is extremely important for learners to be involved in the training. People do not retain information well through passive learning experiences, so trainers must be sure the learning experience is active, involving learners physically, mentally, and emotionally. Through lecture alone, most people will remember a

small amount of what is said. If they are involved in discussions and demonstrations, that retention rate increases. The highest rate of retention comes with immediate use or teaching it to another.

Training for care providers regarding positive behavior support typically includes a number of different topics. Due to the comprehensive nature of positive behavior support, the specific topics depend on the unique needs of the situation. Content often is chosen initially by the trainer with input from the people who are to be trained and other stakeholders. Common topics include:

- Values in positive behavior support.
- Reasons why people with disabilities are more likely to have problem behaviors.
- Knowledge specific to types of disability or mental illness (e.g., autism or borderline personality disorder).
- Creating positive environments.
- Functional assessment.
- Data utility and collection strategies.
- Person-specific strategies.
- Evaluation strategies for plan effectiveness.
- Teamwork.
- Reactive interventions.

Conclusion

Training and technical assistance are crucial components of the effort to support all people in the community. To assure the best possible outcomes, it is critical for behavior specialists and trainers to see their roles as more than reacting to crises, telling people what to do differently, and showing care providers how to hold people down. A partnership must be forged between behavior specialists and care providers, with support for collaboration coming from all.

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Edited by Ronald H. Hanson, Norman A. Wieseler, and K. Charlie Lakin. To be published in summer 2001 by the American Association on Mental Retardation.

This book offers a detailed and comprehensive approach to the knowledge, technologies, policies, and programs that are expanding access to community crisis prevention and response services for persons with developmental disabilities. The volume addresses the challenges of creating community supports that are capable of responding to the needs of all persons with developmental disabilities, including individuals presenting substantial behavioral challenges as well as mental health conditions and personal crises. Containing 13 chapters by 27 authors, many of whom are featured in this Impact, the book is organized into three sections:

- *The Challenge of Community Systems*
- *State and Regional Networks of Behavior Support and Crisis Response*
- *Specialized Programs for Crisis Prevention and Response*

To order "Crisis: Prevention and Response in the Community" contact AAMR at 301/604-1340 (voice), 301/206-0789 (fax), or aamr@pmds.com (e-mail).

Building an Effective Strategy for Crisis Prevention

by Norman A. Wieseler and Ronald H. Hanson

Although crisis response remains an important function of behavior support programs for individuals with challenging behaviors, the ultimate goal for such programs must be to design a behavior support strategy to minimize the possibility of a crisis situation occurring. Crisis prevention requires a coordinated effort to develop an individualized plan for the person at risk. A number of steps are necessary for the development of such a plan, including those below.

The ultimate goal for behavior support programs must be to minimize the possibility of a crisis situation occurring.

Identifying People at Risk

The display of problem behavior patterns is evident to most care providers (e.g., family members, support staff) in their day-to-day interactions with individuals. However, many people's problem behaviors occur intermittently and in situations where a number of different factors may influence the behavior. The frequency, severity, and circumstances of challenging behaviors become the primary considerations in determining whether an intervention plan should be developed.

Identifying Behavior That May Result in Crisis

Aggressive and destructive behaviors, especially when they put others in physical jeopardy, require a crisis prevention plan. Other behavior, although not in-

herently dangerous, may also require a plan for crisis prevention (e.g., removing one's clothing is not inherently aberrant, but if it occurs in public, it becomes problematic). Other behavior may be potentially risky for some individuals or in some circumstances but not others (e.g., walking away from work or home may be an appropriate behavior, but doing so without telling the appropriate person or without possessing the necessary safety skills could subject the individual to dangerous situations).

Identifying Variables Associated with Past Challenging Behavior

Once the behaviors of concern have been recognized, it is essential to determine the factors giving rise to the behavior. Methods for doing so are called *functional assessment* or *functional analysis*. Functional assessment is a team activity that includes using interviews, surveys, or rating scales with those who know the individual best, observing the person in the settings and circumstances in which the challenging behavior occurs, and creating analog situations and noting the frequency of the target behavior under different environmental conditions. Information obtained by interviews, surveys, or rating scales must be supported by direct observation. Because approaches to functional assessment may vary in their usefulness and time expenditure for different persons and situations, it is important for the assessment leader to have experience and practical skill in completing the evaluation. This assessment will define the patterns and nature of challenging behavior, predict its occurrence and nonoccurrence, identify the "functions" it serves for the individual (e.g., gaining release from disliked activities), and describe the responses to the behavior (environmental consequences) that make it "work" for the individual.

Identifying Ecological Variables Associated with Behavior

The physical and social environment in which the individual lives exert a major influence on behavior. It is important that the aspects of the physical environment that promote appropriate and challenging behavior be identified. The role of the people working together to improve the individual's life is to explore, test, and ultimately identify and manage environmental features that influence the occurrence of behaviors that may escalate to crisis proportions (e.g., noise, crowding, fear of another person, lack of privacy, or lack of stimulation).

Identifying Skills That Reduce Likelihood of Challenging Behavior

The absence of appropriate skills by the individual in obtaining recognition from others often results in challenging behavior. It may be effective in obtaining attention, acquiring a preferred item or activity, or escaping from disliked settings or events. If staff react to these behaviors, the problem behaviors become more likely in the future because they produce what the individual wanted (e.g., staff attention, a desired item, or release from a disliked situation). If staff are taught to provide the individual with attention prior to the problem behavior, they are likely to be effective in curtailing the behaviors. If effective in reducing problem behaviors, staff attention is then more likely in the future and both the problem behavior and staff response are reciprocally strengthened. However, short-term solutions can have deleterious long-term effects that make problem behavior more likely. It is, therefore, important to identify and teach alternative ways that people can get what they want and avoid what they do not want. An inventory of skills that would, if strengthened, allow the individual more environ-

mental control must be identified for crisis prevention. It is important for the person to acquire replacement skills that are as efficient and effective as the challenging behavior.

Identifying Environmental Changes That Are Preventative

Planful changes in the physical, social, and procedural features of people's lives can contribute to crisis prevention. The people engaged in such planning must attend to individual preferences ranging from broad aspirations such as movement from sheltered work to supported employment, or from group homes to their own homes. Additional considerations are adjustments in the physical environment to better accommodate the individual's physical needs or the enhancement of community activities to provide more opportunities to develop or foster closer friendships.

Identifying Alternative Skills Needed to Control Challenging Behavior

Teaching appropriate skills that are functionally equivalent to the challenging behavior in acquiring environmental control is an important intervention strategy. The acquired alternative behavior must be at least as efficient and effective as the problem behavior in obtaining environmental control. If the desired behaviors are not, it is unlikely the alternative skill will be demonstrated by the individual. Strategies such as functional communication, self-management, skill building, differential reinforcement of alternative positive behaviors, anger management, progressive relaxation, and development and practice of social skills may become very important in planning crisis prevention for a particular individual.

Developing a Behavior Support Plan for Crisis Prevention

The development of a behavior support plan for crisis prevention requires the coordinated effort of all people engaged

in the individual's life. Many techniques used in the development of an effective plan require the expertise of disciplines not usually available within the interdisciplinary team of service coordinators, family members, direct support staff, and others. Consequently, it is imperative to include in the process consultants with the expertise needed to assist in the development of adequate crisis prevention and response.

Consultants can often be necessary and effective participants in the development of a comprehensive behavior support plan. Their suggestions must be congruent with the direct service providers' values and skills in the sites where implementation will occur. The consultant's challenge is to assist in designing a behavior support plan grounded in the principles of behavior analysis that closely matches person-centered values and the resources of the other family, friends, and professionals in the person's life. This assures the contextual fit between the plan and the values and skills of people who must carry it out.

Although the behavior support plan for crisis prevention is tailored for the individual at risk, it is important that those who develop it recognize that the plan is developed for the care provider's behavior. It is unlikely a support plan will be implemented as written if it is not congruent with implementors' levels of skill, styles of interaction shaped by values, and shared goals.

Support Plan Implementation

It is essential that support plan strategies are embedded in the individual's normal rhythm of life. The personal characteristics of the individual, the values and skills of the care providers, and the nature and demands of the environment in which the plan will be implemented are factors which need to be fully considered. Maintaining typical routines, the person's associations with others, and the activities in home, school, work, or other community settings should happen whenever possible unless it is evident that any of these put

the person at risk of displaying challenging behaviors.

Once the behavior support plan is developed and implemented, maintenance of the plan across settings becomes critical. This requires the team leader or consultant to have frequent interactions with persons playing key support roles in the life of the individual to obtain information about the workability of the plan and comfort level of care providers in implementing it. This interaction allows for a fine-tuning of the components to maintain crisis prevention. When the individual's support providers are involved in the functional assessment and behavior support plan development, contextual fit is facilitated and occurs most naturally.

Conclusion

Each of these steps is important in building an effective strategy for preventing crisis situations. To be optimally effective, each person involved in supporting the individual must share the common goal of preventing crisis situations rather than only responding after the crisis has occurred. The opinions of each, regardless of their relationship with the individual or their professional status, must be valued and considered when planning for crisis prevention. Having an effective behavior support plan designed from the experience and suggestions of all those engaged with the individual helps to ensure the person's continued success in remaining in the community while also assuring attention to his or her right to pursue a high quality of life.

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Ten Years of Prevention: The Vermont Crisis Intervention Network

by Patrick Frawley and Elia Vecchione

With the national movement toward deinstitutionalization, community-based crisis services for persons with developmental disabilities have become increasingly important. This article briefly describes the Vermont Crisis Intervention Network (VCIN), a statewide crisis prevention and intervention program that originated in 1991.

Vermont is a very small and rural state, 157 miles long and only 90 miles at its widest point. Within this area lives a well-spread out population of just over 600,000 people. This combination of population and geography allows for easy statewide communication and cooperation. Throughout Vermont there are nine full-service Community Mental Health Centers with programs for persons with developmental disabilities, as well as six smaller agencies that provide only developmental disability services. These agencies together currently serve an estimated 2,400 consumers in the state's communities.

The Vermont Crisis Intervention Network's primary function has always been to prevent the institutionalization of any Vermont resident with developmental disabilities. Beyond this goal the program strives to enhance the clinical services provided to these individuals through the service system in Vermont. This is attempted through a three-tiered service approach. Within the first level, prevention oriented services are provided. At Level II early intervention efforts are evident, and at Level III short-term community-based, crisis residential services are utilized. The network, in collaboration with all of the dedicated community agencies serving individuals with disabilities throughout Vermont, plays a vital role in the maintenance of the stability of the community system.

Level I: The Clinical Network

There are not enough highly trained clinicians practicing within Vermont to cover all of the agencies serving persons with developmental disabilities. Therefore, in order to reduce, and potentially prevent, crises throughout the state the level of clinical expertise within the agencies must be increased. This founding premise was true in 1991 when VCIN was started and it is certainly still true nine years later. There is only a handful of clinicians within Vermont who are capable of providing sophisticated clinical consultation concerning the challenging behavior and dual diagnosis issues presented by persons with developmental disabilities. The occurrence of crises, and especially the need for the relocation of a person with developmental disabilities from his or her home, can be dramatically reduced through the increasing of clinical competencies of the agency staff. A clear primary prevention orientation is evident within Level I.

For the first eight years of the program the primary service within Level I was the clinical network meeting. This monthly gathering allowed for the primary clinical staff from each agency to come together on a regular basis. This year, due to lagging participation, we have redesigned this service to focus upon small semi-annual conferences with a clinical focus. Other functions of Level I include trainings, which may take place at a community agency or may involve specifically selected participants.

Level II: On-Site Consultation

In order to reduce or prevent crises, competencies of clinical staff, direct service staff, and case managers can be increased through on-site consultation. Within Level II, expert clinical services are provided to agency staff at their location and in reference to a specific indi-

vidual. Most of the Level II activity involves psychological or psychiatric consultation to teams addressing the issues of challenging behavior or dual diagnosis. This is clearly early intervention.

Level II consultation through the network involves a flexible but fairly consistent format. A referral may come from anywhere – state personnel, agency staff, parents, or others. The primary consideration is that the person being referred must qualify for developmental services within Vermont. Depending on the demands of the consultation, one or more of the professional staff may become involved. Some require both psychological and psychiatric expertise, but often the request is for one or the other. As is true in Level I, raising the competence of local staff is among the primary interests of our consultants at Level II. This is a bit more challenging at Level II, where the dynamics at play seem to try to force us into an expert role, dictating plans to staff. Yet, it is important that when the consultation is completed, the staff have learned new skills and have had their confidence raised in their own abilities to solve clinical issues.

After collecting some interview information from staff or case managers, we always spend a good deal of time reading the records of the consumer we are there to assist. Essential information about the history of the problem behavior is often contained in the record. This includes medical issues, medication histories, behavioral treatment histories, and psychotherapy notes. Following the record review our consultant usually spends a good deal of time observing and interacting with the consumer and his or her staff, family, and so forth.

After all of the information has been collected by the consultant, we convene a team meeting to discuss the situation. These meetings include direct care staff, home providers, case managers, and

parents and/or guardians. It is in these meetings that an understanding of the situation is agreed upon by the participants and a plan is developed. Many times this phase of the process requires that the participants read a good deal of information about the problem behavior and potential solutions. Often direct service staff, parents, and service coordinators read very technical, clinical articles during this portion of the consultation. It is of the utmost importance that the plan be designed and agreed upon by those who must carry it out. Though there is often a great push to have the consultant devise and write the plan, a plan developed by a consultant is almost always doomed to failure. The people who have to implement the plan must be invested in it and this is best accomplished by their designing and writing it, with necessary assistance.

After the plan is developed and implemented it is important to have ongoing meetings to discuss problems, successes, and modifications to the plan. Depending on the situation, our consultants may follow a team for as long as a year, or may be done after a meeting or two. We provide consultations to approximately 50 individuals every year.

Level III: Residential Crisis Services

At times, for a variety of potential reasons, it will be necessary for an individual to leave his or her home. Therefore, for a full community system to operate properly, it is essential to have an alternative setting, offering safe housing, evaluation, and treatment.

Throughout the nine years of the VCIN program, we have had a steadily decreasing number of residential crisis options. In the first year of the program we operated two well-staffed, full-service crisis beds and we also offered four respite options which could accommodate individuals with less acute demands. These options were reduced until we were left operating just one bed in the summer of 1995. These decreases of VCIN resources were a direct result of the increased crisis capacities within the

community agencies.

Located on a dirt road in the country, our crisis bed is a two-bedroom, two-story home where only one consumer at a time resides. It is staffed 24 hours per day by one VCIN staff person at a time. Approximately 3.5 full-time equivalent staff are required to operate it in a rotating shift pattern. While a person stays at the residence they are provided with as meaningful a day schedule as possible.

While residing in our crisis house an individual also receives the clinical services described in Level II. In order to facilitate continuation of treatment begun during a person's stay with us, Level II consultation services are almost always provided in a follow-up fashion once a person leaves.

The sending agency staff, who retain the service coordination role, are responsible to attend a weekly clinical meeting regarding the person residing within the crisis house. The program tries to stick to a 30-day limit, although this is certainly flexible depending on the situation. Annually we serve from 10 to 15 people in this bed, with an average stay of about 22 days. We feel that through Level III we offer people who are in crisis a safe, humane, and clinically sophisticated environment in which they can become stabilized, receive evaluation and/or simply take it easy before returning to their lives within the community.

Dianne's Story

For nine years the developmental disabilities service system within Vermont has collaboratively provided prevention, early intervention and crisis residential services to its residents with developmental disabilities, such as Dianne.* Dianne was a teenage girl who had experienced a traumatic life of abuse and multiple residential placements. We were called by an agency that was having trouble meeting her needs. She was living with a very dedicated couple who were struggling with some of her challenging behavior. Our Level II consultation to Dianne and her team followed

the customary route, with record review, interviews, and observations. The main issue was that she had great difficulty controlling herself when she became upset about anything. Our consultant provided extensive training to Dianne's team regarding issues of trauma and abuse, attachment, and anger control.

During the course of our consultation, Dianne engaged in some very destructive and aggressive behavior that resulted in her home providers deciding she could no longer live with them. The agency that served her did not have any crisis or respite options available, so they requested a stay at our crisis bed.

Dianne stayed in our Level III service for over a month. She was provided with different medication by our psychiatrist and received short-term anger control treatment. She responded well to her stay with minimal disruptive behavior.

A new agency began a search for a new home for her, and found two potential providers. Both spent time with Dianne, first at our house and then at their homes, and both were interested in having her live with them. Dianne had a stronger liking for one, and her guardian agreed that the home she had selected was a good choice. We began having Dianne spend more time at her potential new home, with some overnight stays. Finally, she moved in.

We continued to provide Level II follow-up services to Dianne and her new home providers. Her case manager had trouble finding a new therapist to continue the anger control treatments, so we offered to provide them until a new therapist was found. Dianne continues to do well in her new home with only minimal contact from VCIN.

* Pseudonym

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Behavioral and Crisis Services in California

by Gregory A. Wagner

With increasing rates of deinstitutionalization, resulting institutional closures, and mandates to use community referenced, “socially valid” procedures to manage and treat challenging behavior, community settings have come under increasing pressures to support people with challenging behavior in the least restrictive means possible. These realities are no different in California than anywhere else. Indeed, recent events have exacerbated these issues in California.

Currently, the California system serves over 160,000 persons, approximately 3,800 of whom are served in the state’s institutions.

These events include a class action lawsuit that increased the rate of deinstitutionalization and resulted in institutional closures. This article briefly describes the California service system and recent deinstitutionalization activities and consequences with regard to community behavioral and crisis supports.

The California Service System

In California, the Lanterman Developmental Disabilities Services Act entitles all persons with developmental disabilities in the state to receive appropriate services. This law also provides for the creation of a statewide regional center system. The regional center system consists of 21 private, non-profit locally-based centers with whom the state contracts. These regional centers are the point-of-entry into the developmental services system for the 58 counties in California. Their role in the system is to coordinate services and supports

through generic agencies, or directly fund services and supports. In addition to individualized planning and service coordination, services provided directly by regional centers include assessment and diagnosis, information and referral, advocacy, and resource development. The state directly administers five institutions (developmental centers), and two smaller, specialized behavioral facilities, each serving 50-60 persons. Currently, the system serves over 160,000 persons, approximately 3,800 of whom are served in the state’s institutions.

In the late 1980s, Regional Resource Development Projects (RRDPs) were created at each developmental center to assist regional centers in developing and enhancing services and supports for persons moving into community settings. Each of these RRDPs consists of several state employees who fill a number of roles. For example, these projects monitor persons placed from developmental centers into community settings for the first year of placement, provide a variety of community training opportunities, and provide and/or assist in securing and coordinating clinical services.

Deinstitutionalization

The history of deinstitutionalization in California is very similar to national trends with regard to overall rate. Despite an overall downward trend, however, the developmental center census remained relatively constant from 1987 to 1992. In 1993, a class action lawsuit (*Coffelt v. DDS*) was filed against the Department of Developmental Services and four regional centers, alleging that too few community living arrangements were being created, resulting in people residing in unnecessarily restrictive institutional settings. A major requirement of the resulting settlement was the reduction in developmental center population by 2,000 people (from approximately 6,000) in a five-year period

(1993-1998). This reduction actually took place in two and one-half years, well ahead of schedule. In the process, two centers were closed.

Crisis and Support Services

The increased rate of placement resulting from the *Coffelt* settlement mentioned above put increased pressures on community crisis and behavioral support systems. In anticipation of these pressures, the settlement included provisions for enhanced crisis intervention services. These provisions required each of the 21 regional centers to develop crisis service proposals. The proposals were based on an initial assessment of local and regional, public or private emergency and crisis services, and corresponding gaps in each geographic area. In addition, crisis proposals were developed through collaborative meetings with relevant agencies (e.g., mental health), providers, and consumers. Finally, the respective roles and responsibilities of the various agencies involved in providing crisis intervention services were delineated (i.e., who is responsible for providing and/or paying for specific services). Plans included provisions for crisis intervention teams, emergency housing, and regional center after-hours response systems.

In 1998, many of these and other provisions were written into law. For example, if a consumer’s placement is failing and admission to a developmental center is likely, the state must arrange for an immediate assessment of the situation, and ensure that the responsible regional center provides necessary emergency services and supports, and convenes an Individualized Program Plan (IPP) meeting of the individual’s service coordinator, service providers, family members, and other key persons as soon as possible. Additional language was written into law to focus on persons with dual intellectual and psychiatric

disability diagnoses. These requirements included memoranda of understanding (MOUs) between each of the 21 regional centers and the local county mental health agencies. These MOUs: (a) identify staff in both agencies who are responsible for identifying consumers with dual diagnoses “of mutual concern” and coordinating services for those persons; (b) include a crisis intervention plan with after-hours emergency response capability; (c) include procedures for joint clinical and discharge planning for persons admitted to inpatient mental health facilities; and (d) provide for training of residential and day program staff regarding effective services for persons with dual diagnoses.

Within these general systemic requirements of emergency and crisis services outlined above, a variety of specific preventive and reactive strategies have been implemented. Some examples of specific strategies and activities include:

- Some regional centers have developed consumer “risk profiles” to assist service coordinators and providers in predicting and intervening at early stages of potential behavioral crises. These profiles include environmental antecedents and behavioral precursors predictive of crises.
- Regional centers often maintain lists of behaviorally high-risk consumers, with information on effective strategies with each consumer, and local crisis and emergency services. This information is typically provided to on-call staff via laptop computers.
- Regional centers commonly hold routine multidisciplinary staff meetings to identify at-risk consumers, develop individual crisis plans for those consumers, and problem-solve current difficult cases (e.g., consumers who are at risk of relocation, especially admission to a developmental center; incarcerated; in a psychiatric hospital). In addition, some have internal intensive support services units or pre-crisis screening teams.
- Many regional centers provide enhanced service coordination (i.e., reduced caseloads) for consumers who have been recently placed into community settings from developmental centers and/or have extremely challenging behavior.
- While regional centers primarily coordinate and/or broker necessary services and supports, recent funding has provided for the addition of clinical teams to the centers, allowing for the provision of increased direct services by regional centers staff (e.g., behavioral, medical, and psychiatric). Also, regional center service vendors (behavior analysts, pharmacists, psychiatrists, including University Affiliated Programs) provide additional clinical services.
- In addition to regional center staff and vendors, state development center and Regional Resource Project staff provide clinical outreach services (e.g., behavioral consultation, medication review), training (e.g., managing aggressive behavior, teaching new skills), and technical assistance (e.g., meeting regulatory requirements, obtaining needed resources). Also, developmental centers have university-based psychology internship programs in which interns, under the guidance and supervision of a developmental center psychologist, provide assistance in transitioning people into the community, and in community behavioral services for consumers whose challenging behavior threatens their placement. These services include functional assessments, development of behavioral plans and strategies, direct therapeutic interactions, and staff training and consultation.
- Interagency collaborative meetings are held in some parts of the state, with participants from regional centers, mental health, criminal justice, and so forth, and training opportunities, workshops, and seminars are provided to those agencies, providers, and families regarding behavioral, psychiatric and crisis issues.
- Telemedicine (e.g., psychiatric and

psychotropic medication consultations) has been effectively incorporated into some rural locations, and its use continues to increase.

- Enhanced staffing (including one-to-one with corresponding plans to fade the staff) may be used.
- Peer mentors have been arranged for providers and families with behaviorally challenging consumers.
- Person-centered planning is now required by law as a framework for developing IPPs.

To evaluate the overall quality of services and supports, and consumer satisfaction with those services and supports during the implementation of the *Coffelt* settlement, a longitudinal study of a sample of class members was conducted. With respect to reported satisfaction with behavioral and crisis services, supplemental supports (e.g., in-home behavioral consultation and intervention, enhanced staffing, etc.) and regional center after-hours phone response tended to get the highest ratings across years, while (not surprisingly) incarceration and emergency rooms received the lowest ratings. A small percentage of people also indicated needs for greater access to mental health counseling/therapy, including access to psychiatrists, and medication adjustment.

Summary

Supporting people with significant challenging behavior and psychiatric needs is difficult in any setting. The supports and services described in this article share many elements with successful models elsewhere. As the trend toward full community inclusion continues, the need for effective, community behavioral services and supports, and psychiatric interventions, will only increase.

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Collaborative Services in Massachusetts: The START/Sovner Center Program

by Joan B. Beasley

START – an acronym for Systemic, Therapeutic, Assessment, Respite and Treatment – has been providing clinical, emergency, and respite services since 1989. The Massachusetts Department of Mental Retardation (DMR) funds the START program in order to provide community-based crisis intervention and prevention services to individuals with developmental disabilities and behavioral (mental) health care needs in the northeast part of the state. START and the Robert D. Sovner Behavioral Health Resource Center of which it is a part serve a region of approximately 750 square miles and 1.1 million total residents. Over 1200 individuals have used Sovner Center and START services.

The program's underlying philosophy is that services will be most effective when everyone involved in care and treatment is allowed to participate actively in treatment planning and service decisions. In order for this to occur, collaboration between service providers and with service users is necessary, and an integral part of the program.

START Services

In order to access appropriate mental health services and to facilitate a coordinated service approach and foster service linkages, START provides a number of opportunities for consultation, education, and individualized treatment planning. START also provides a number of services to coordinate care and fill in service gaps. The services include collaborative contacts, after-hour contacts, emergency team meetings, planned respite, and emergency respite services:

- **Collaborative Contacts:** Collaborative contacts are made up of crisis prevention planning meetings, consultation visits, treatment planning meetings, and follow-up meetings. START clinicians are required to fa-

ilitate individual crisis prevention planning meeting at least once a year. Whenever possible, the START clinician, the service user, members of the mental health service team (i.e., the outpatient therapist, a representative from the mental health crisis team, the psychiatrist), members of the developmental disabilities service team (i.e., the service coordinator, residential and day program providers), and the individual's informal or social supports (family members, friends, and other interested parties) meet to develop a plan to assist the individual and his or her caregivers during times of difficulty. START clinicians are also required to maintain ongoing contact with family members and other caregivers. Follow-up meetings are scheduled to evaluate the effects of treatment strategies, update crisis prevention plans and to foster active communication among providers and with direct caregivers.

- **After Hours Contacts:** START provides 24-hour mobile crisis services. After hours (5 p.m. – 9 a.m. Monday through Friday and all weekend), START clinicians rotate on-call responsibilities and are available to provide assistance to families, DMR, psychiatric pre-screening teams, and residential providers 24 hours a day, 7 days a week. After-hours contacts may include phone calls to assist during a time of crisis, clinicians providing mobile evaluation services and assisting a mental health crisis team to determine whether or not a psychiatric inpatient admission is needed, assistance locating an available inpatient bed, or pre-screening the individual for an emergency respite admission.
- **Emergency Meetings:** Emergency meetings are team meetings facili-

tated by START clinicians on a psychiatric inpatient unit or at the emergency respite facility following an admission. The meetings are scheduled within 24 hours of the admission or the next business day whenever possible. The purpose of the meeting is to allow the START clinician and other members of the team to provide information to the inpatient unit in order to assist with treatment and disposition planning. Family members and residential providers are strongly encouraged to participate in the meeting. In addition, the START clinician attempts to facilitate phone contact between the individual's outpatient and inpatient psychiatrists, and encourages ongoing contact between the family and residential provider throughout the admission. Whenever possible, a discharge planning meeting is also scheduled to ensure a smooth transition back home.

- **START Respite:** START respite is a place where people can live for short periods of time when they are in distress or in need of support and assistance. The START respite facility is staffed with a full-time director, a weekend coordinator, direct care specialists, and awake overnight staff. The staffing pattern is 3:4 during "awake hours" (8 a.m.– 10 p.m.) and 2:4 during "sleep hours" (10 p.m.– 8 a.m.). However, one-to-one staffing is provided as needed. The respite center has private bedrooms, and one bedroom has a private bath. It is divided into two wings so those individuals who have more severe difficulties do not disturb or become disturbed by other guests. Additional facility-based emergency respite is provided by independent affiliates of START. They maintain the same staff to guest ratio, and work closely with START personnel.

- Planned Respite Services:** Two of the beds in the four-bed respite home are designated as “planned respite beds.” Planned respite beds at START are intended to serve individuals who have not been able to use respite in more traditional settings due to their ongoing mental health and/or behavioral issues. Families participating in the program must be approved by DMR as eligible for these services, but once approved, they schedule visits as needed and as space is available. Planned respite visits are provided to any START service recipient and are not restricted to people living with their family. An individual can visit respite for dinner, a recreational activity, or to just “check in” for a few hours. Some families visit respite with the guest to become familiar with the facility and staff prior to scheduling overnights.
- Emergency Respite Services:** Emergency respite services are provided at the START respite facility. Two beds in the four-bed respite facility operated by START are designated for emergency respite purposes. Emergency respite is designed to provide out-of-home housing and services to individuals who for a short period of time (suggested 30 days or less) cannot be managed at home or their residential program. Additional emergency respite services are purchased on an as-needed basis from START affiliates.
- Psychiatric Inpatient Services:** Community mental health hospitals and general community hospitals provide psychiatric inpatient mental health services. Inpatient psychiatric services are expected to be very short term (seven days or less). Inpatient psychiatric services are primarily provided by three hospitals in the region. The hospitals have affiliation agreements to coordinate services with START and DMR representatives. The affiliation agreements are with the hospitals that provide the bulk of the inpatient services to

people with developmental disabilities in the region. However, other hospitals also provide some psychiatric inpatient services. START clinicians offer the same services at these times. In order to access needed services, START relies upon the use of affiliation agreements and linkages with the developmental disabilities and mental health service systems, and the individual’s natural support system.

Nearly 20 years ago, the late Frank Menolascino recommended a “systematic” approach to the management of behavioral health needs of persons with developmental disabilities, including the provision of comprehensive diagnostic evaluations, active family involvement and education, early diagnosis and treatment, vocational services, residential services, and family support with short-term crisis care facilities to provide back-up support when needed. He stressed that “Coordination of the many services needed for individuals with dual diagnoses requires awareness of the various services available in a given community and a professional attitude that permits active collaboration. It necessitates sharing of the overall treatment plan with the individual, the family, and with community resources. Close attention to the clarity and continuity of communication is essential” (Menolascino et al. 1983). START is one model of a “systematic approach” to care as described by Menolascino and others to assist people with developmental disabilities and behavioral health care needs in the community. The guiding premise of START is that the individual’s needs and wishes drive all services and supports, while the coordinated linkages fill service gaps and allow for the use of multiple services and service systems through proactive communication and collaboration. Jimmy’s story, below, helps to demonstrate how START works with individuals who have developmental disabilities and behavioral support needs.

Jimmy’s Experience

Jimmy* is in his early 20’s and has moderate cognitive impairments and autism. He has lived with his family all of his life, and they would like to continue to have him with them. They have tried to access family support for many years, but Jimmy has not been able to use traditional out-of-home respite services available to other DMR service recipients because of ongoing severe self-injury and major property destruction.

Prior to Jimmy’s referral to START, his family was in constant crisis. His behavior problems were severe and out of control. He was hospitalized in psychiatric facilities on numerous occasions, and after each admission seemed worse. He was referred to the START team and Sovner Center clinic, and upon arrival the family expressed doubts that they could continue to manage the situation.

Jimmy and his family received services from START, and since working with the START team, he has been diagnosed and successfully treated for obsessive-compulsive and bipolar disorders, and his behavior has improved dramatically. He continues to receive support staffing through a DMR provider agency in the family home, and members of the START team provide ongoing training and support to his direct service staff. A START clinician attends Jimmy’s psychiatric appointments to assist in communicating with his psychiatrist, and also talks with his day program provider to ensure that everyone on his team is in communication with regard to Jimmy and his mental health care needs.

Jimmy continues to have ongoing challenges, however, he and his family are no longer in constant distress. The system is linked, communication is active, and everyone continues to benefit from this approach – especially Jimmy.

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*Pseudonym

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Human and Cost Benefits of Community Behavioral Support in Minnesota

by Joan Oslund, Wayne Larson, and Charlie Lakin

Minnesota entered the 1990s with a goal of rapidly moving people from state institutions to community settings and of eventually closing the institution doors behind them. Between June, 1990, and June, 1995, Minnesota's state institution population decreased from 1,337 to 524 people. During the same period an average of 122 people were admitted to state institutions each year. The vast majority (77% in 1994) were admitted for short-term stays of less than 90 days in response to behavioral crises and other emergencies. Minnesota's legislature recognized the need to end this pattern of admissions, and authorized funding for a community behavioral support and crisis response demonstration program, specifying that it be evaluated for its ability to reduce institutionalization in a cost-beneficial manner.

Special Services Program Design

The Special Services Program (SSP), was established as the authorized demonstration. It targets five counties in the Minneapolis area, and its primary goal is to prevent institutional and other out-of-home placements due to behavioral episodes or emergency circumstances at equal or lower costs than more restrictive residential treatment. Achieving these goals requires two types of services: outreach in the individual's home, workplace, school, or other community setting; and short-term (90 days or less) inpatient treatment in a specialized unit. Both involve an interdisciplinary team focusing on non-aversive behavioral interventions guided by a functional assessment of challenging behavior. The program staff include a director with extensive experience in mental health, two behavior analysts, a psychiatric nurse, an intake worker, and experienced direct care staff in the crisis unit. Ongoing consultation is provided by a board-certified

psychiatrist and licensed psychologist. This team is able to assess a range of environmental, medical, psychiatric, psychological, and communicative factors.

Outreach services include functional assessment of the behavior for which the individual is referred, technical assistance in devising appropriate interventions, and care provider training. The residential unit provides intensive support and intervention for individuals whose behavioral challenges have seriously jeopardized (or resulted in loss of) current residential or other service situations. Consultation is provided by the SSP staff on long-term planning of more appropriate accommodations or enhancing supports to permit the individual to return home. The short-term crisis unit is staffed 24 hours per day and can accommodate four people at a time. To the extent feasible these persons maintain their school, work or other activity while living on the unit.

Outreach and crisis unit services are provided in three phases: 1) assessment; 2) intervention/training (including the development of a crisis prevention/intervention plan); and 3) follow-up. The foundation of the assessment and intervention process is the instruments and procedures designed by the Institute for Applied Behavior Analysis:

- **Assessment.** Originally, the assessment was designed to be brief, but intense, so that preliminary recommendations could be developed and presented to interdisciplinary teams within one week of service commencement. With the development of the Metro Crisis Coordination Program for the more urgent situations, the assessment has become more comprehensive and therefore the timeframe has expanded to 30 days or less. Assessments are conducted by a behavior analyst and a

psychiatric nurse, and include individual and group interviews with family members and service providers, a records review, and direct observation of referred persons in their home and day setting.

- **Intervention/Training.** Recommendations for intervention and training include a) proactive strategies; b) environmental modifications; c) reactive/emergency strategies; d) staff/care provider training; e) data collection; and f) follow-up. Intervention strategies concentrate on the developing alternative social and communication skills, and environmental conditions that may affect behavioral patterns. Often additional recommendations are received from the consulting psychiatrist and psychologist. Referrals may be made to other medical specialists or to communication specialists. Reactive strategies are also devised to intervene in challenging behavior. These include crisis prevention plans to assist families and service providers. Ongoing consultation regarding the implementation of specific interventions is provided. As possible, the SSP directly or via other specialists in the community provides educational materials and training on specialized issues.
- **Follow-up.** The SSP team follows referred individuals for a year from service commencement. Follow-up enables SSP to keep informed of the individual's adjustment following services, offer assistance, and maintain evaluation of service effects.

Special Services Program Outcomes

Evaluation results have shown diversity in persons served, general effectiveness in services offered, and cost-benefits for

Special Services Program as a whole:

- **Individual Characteristics.** The most common behavioral concerns at the time of initial referral have included: physical aggression toward other persons (71%); verbal aggression (50%); property destruction (26%); and self-injurious behavior (21%). More than three-fourths (82%) of all persons referred have had a psychiatric diagnosis, most frequently schizophrenia or other psychotic disorders, personality disorders, affective disorders, and impulse control disorders. The ethnic composition of referrals is similar to that of the Twin Cities metropolitan area. Referred individuals have ranged in age from 8 to 67 years, with an average of 29.6 years. A quarter of persons referred were less than 17 years old. Two-thirds (67%) were male.
- **Placement Effects.** Fifty-eight percent of the individuals served via outreach services, but only 25% of the crisis unit users, have remained in the same residential setting throughout the whole year following initial referral. By the end of 1994, one of the 24 individuals who had been admitted to and discharged from the SSP unit had entered an institution; this was early in the program when a local agency did not develop a home for a crisis unit resident within 90 days as required, and SSP decided not to deviate from the established requirement. In comparison, in 1994 3 of 14 individuals unable to access SSP services because of limitations on capacity or from being outside the catchment area were placed in a state institution for long-term placement.
- **Satisfaction.** Post-service telephone interviews have been conducted with 32 primary care providers of persons receiving SSP services. Fifty-six percent rated their overall satisfaction as "very high" and 44% rated it "high." Four-fifths of care providers gave staff "very high" satisfaction ratings. Of 46 service coordinators interviewed in the evaluation, 63% rated

their satisfaction with services as "very high" and 37% rated it "high." The specific dissatisfactions most often revolved around the time lapse between referral and initiation of service. The 90-day placement limit for crisis unit services was also considered by some to be too short to develop new residential programs for people who were unable to return to their previous home, a criticism which led to development of transitional housing options.

- **Cost Effectiveness.** Estimates of the cost effectiveness of SSP are based on projections of the most likely service disposition for each SSP referral in the absence of the program. These projected outcomes were obtained through interviews with each individual's service coordinator. Dispositions are stated in terms of residential and other support services and their probable length that would have occurred. Expenditures are estimated based on average costs for those services in the area. Alternative dispositions are limited to a 90-day period from referral because of lower reliability of longer projections.

It is projected that 27 of 54 individuals completing SSP services would have been placed on a short-term basis (90 days or less) in an institutional setting. The estimated costs projected for persons who were served in the crisis unit had the unit not been available are \$414,619 or \$20,731 per person. Expenditures of \$307,703 or \$9,050 per person are projected for persons served off campus had the services not been available. Thus, the average projected alternative expenditures for SSP participants are \$13,376 per person.

Actual expenditures for SSP operations were \$435,148, including \$26,553 for 1,308 resident days on the crisis unit (89.6% of full capacity). The net projected expenditures for SSP participants in the absence of the program are \$722,320. It is estimated that annual costs for SSP par-

ticipants are \$287,172 less than likely costs in the absence of SSP (i.e., \$722,320-\$435,148).

- **Validation.** While there are no better sources of likely outcomes in the absence of SSP than those of individuals' service coordinators, it is important to validate their projections. This has been done through follow-up on 14 individuals who were unable to access SSP services because of limited capacity and catchment area restrictions. Because these individuals were similar to those persons served in the SSP, their actual experiences were used to test the accuracy of the service coordinators' projections. Seven of the 14 individuals were admitted on short-term basis to a state institution and one was placed in a psychiatric hospital. This yielded a per person average estimated expenditure of \$13,273 in the absence of SSP, nearly identical to average projected expenditures of \$13,376 for SSP participants in the absence of the SSP. This provided strong support for the service coordinators' projections of outcomes and expenditures in the absence of the SSP.

All the evaluations of the SSP model have shown it demonstrated success in preventing institutionalization, satisfying care providers and service coordinators, and saving service dollars. The extensive needs of individuals and the gaps in the present service system have become obvious, and SSP has demonstrated an effective response.

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Use of Telemedicine to Provide Ongoing Consultation to Care Providers

by David P. Wacker and Anjali Barretto

Since 1985, the Biobehavioral Outpatient Service has operated in the Department of Pediatrics at the University of Iowa Hospital School for children and adults who have developmental disabilities and engage in challenging behavior. The focus of the clinic is to assess challenging behavior via functional analysis methods and then to develop interventions based on functional communication training. We have conducted evaluations of approximately 127 children and adults this past year, most involving evaluations of self-injury or aggression.

Two practical concerns have emerged about the services we provide in the outpatient clinic. First, only about half of the patients show any problem behavior in the clinic. This is not too surprising, given the novelty of the situation, the uniqueness of the day, and other factors such as the undivided attention the patient often receives from care providers. Second, families often travel over 100 miles one way to attend the clinic. This length of travel can put added stress on an already stressed family and often precludes any follow-up through the clinic. Although we are strongly committed to the functional approach we are using in the clinic, we believed that our method of delivering that approach needed to be changed.

In 1997, we were given the opportunity to deliver the same functional model used in our clinic via telemedicine, which utilizes interactive video. In Iowa, studios with interactive video capability are located in most high schools and regional hospitals. It seemed possible to us that the functional model used in our outpatient clinic could be conducted over interactive video, with the major benefits being the cost and time savings to families.

The Telemedicine Process

Telemedicine services at University Hospital School include both initial and follow-up evaluations. In addition, we conduct discharge conferences, wrap-up sessions following outpatient evaluations, and consultation with local school teams. The initial evaluations are similar to those conducted in our outpatient clinic and focus on identifying environmental variables maintaining problem behavior. These types of evaluations consist of a descriptive assessment (e.g., A-B-C interview) followed by a brief functional analysis. A typical initial evaluation lasts 90 minutes (the same duration as an *in vivo* clinic evaluation), with the first 15 minutes being devoted to conducting an A-B-C interview to gather information about environmental events surrounding the target behavior. This information is then used to formulate a hypothesis regarding the function(s) of the target behavior. We then conduct a brief functional analysis to test this hypothesis. Following the assessment, we conduct a brief wrap-up (via telephone or as part of the session) to summarize the results of the assessment and to provide recommendations for intervention. We have conducted four such evaluations over the past year in collaboration with Des Moines Public Schools in Iowa located over 100 miles from our clinic. We have up to 10 more evaluations scheduled for this school year, each of which will consist of both a descriptive assessment (A-B-C assessment) and a functional analysis.

Some of our initial consultations consist of interviews with care providers to identify possible environmental variables maintaining target behavior and the initiation of ongoing assessment in the home or classroom. Based on the information obtained during the interview, we provide recommendations, devise observation forms to gather relevant

information over a period of time, and demonstrate their use. These data are then sent to us by fax, e-mail, or regular mail. We review the data and provide consultation on our interpretation of the outcomes of these observations.

Follow-up evaluations consist of ongoing consultation by our clinic team. These types of evaluations may occur after an initial evaluation has been conducted via telemedicine (as described above) or following on-site clinic or inpatient evaluations. Our experience and that of the families have convinced us that the vast majority of follow-up evaluations can be conducted using telemedicine. Surveys of both participating families and those who attended the on-site clinic rated the quality of service about the same. However, the cost saving to the family is substantial for telemedicine. Given equal quality and increased cost savings, we believe that telemedicine should be used even more.

To date, we have consulted with over 40 families via telemedicine and have conducted approximately 100 evaluations (both initial and follow-up). The duration of consultation has been from one session to fourteen sessions over a two-year period. As part of the funded project we agreed to conduct 25 evaluations, but we actually conducted just over 75 more evaluations simply because as professionals we were very satisfied with the quality of service we could provide and because of the enthusiastic response by consumers of the service. Additionally, the use of telemedicine has made it very possible for local service providers to "attend" the evaluations. With consent from the family, educational consultants and medical staff routinely "join in" from area studios (multiple sites can participate). As a result, we currently enjoy a very strong professional relationship with educational and medical teams.

To further highlight the telemedicine service, we provide an example of its use with one child, Karl, who was diagnosed with autism and deafness. This example demonstrates how useful telemedicine can be with the most challenging cases. It also shows how families and professionals can work more closely together over extended time periods, even when physically located many miles apart.

Karl's Story

Karl* was eight years old when we began working with him and lived with his parents and sister in a town about 75 miles from University Hospital School. In March, 1988, Karl was referred to the Biobehavioral Outpatient service by his family physician and his parents for an evaluation of self-injury (e.g., head banging, eye poking), aggression (e.g., hitting others), destruction, stereotypy (e.g., key twirling), and lack of independent toy play. During the initial evaluation in our outpatient clinic, we conducted a brief functional analysis to identify the environmental variables maintaining Karl's challenging behavior. While in clinic, Karl's parents conducted the sessions with assistance from clinic staff. The result of the functional analysis showed that self-injury served several social functions (e.g., to gain preferred items or to escape nonpreferred activities). We also observed that Karl wandered around the room and resisted his parents when they attempted to engage him in an activity. Based on these results, we recommended a treatment package that included structured work and play situations, choice making, functional communication training, and extinction. We demonstrated these procedures in clinic and described them in written recommendations to the family.

We believed that ongoing follow-up would be helpful, as numerous changes to treatment would be needed. In essence, we viewed the treatment package recommended from the clinic evaluation as a baseline plan upon which we would build. Our first follow-up evaluation was scheduled for April, 1998, to determine

the efficacy of our initial plan. All those involved in Karl's care (e.g., his parents, in-home therapist, teacher, speech therapist, family physician) "attended" this session from the local school and hospital. During this follow-up evaluation, Karl's parents and the in-home therapist raised several good questions regarding problem behavior that occurred in specific situations. This led to a series of routine follow-up evaluations over the course of a two-and-one-half year period. Karl's parents also videotaped situations that were problematic, which helped us provide them with other recommendations. They also sent us videotapes of Karl's progress, which was remarkable. Overall, during the initial treatment and the follow-up he moved from self-injury, aggression, destruction, stereotypy, and lack of independent toy play to engaging in up to 30 minutes of independent play, using a communication device, following hitting with appropriate touching and signing for the preferred item, and self-scheduling activities during breaks. This was in large part due to the extensive follow-up available to Karl that would not have been possible without telemedicine.

Summary

Our hope is that telemedicine will bridge the gap between families, local service teams, and highly specialized professionals in addressing the needs of individuals with challenging behavior. In this way, all families can have more immediate access to professionals who have specialized expertise.

*Pseudonym

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Resources of Interest

- **Rehabilitation Research and Training Center on Positive Behavioral Support Web site (<http://rrtcpbs.fmhi.usf.edu>).** *The center's Web site provides extensive information on definitions, features, and procedures in positive behavioral supports, along with documents including "Benchmarks of Effective Practice in Positive Behavioral Support."*
- **Online Academy on Positive Behavioral Support Web site (<http://onlineacademy.org/acad/products>).** *This Web site includes seven modules of online instruction related to providing positive behavioral supports. Topics include functional assessment, intervention strategies, redesigning environmental systems, and creating positive lifestyles.*
- **Journal of Positive Behavior Interventions.** *This relatively new journal is focused on applied research in positive behavioral assessments and interventions that are based in and/or have direct applications to natural settings. It is published by PRO-ED. Information about previously published and upcoming articles is available at <http://www.education.ucsb.edu/~autism.JPBI.html>.*
- **QualityMall.org.** *This Web site is designed to help users find innovative products, programs, and practices related to providing person-centered services in community settings. The "mall" is divided into 18 "stores" with over 70 departments. In the Health and Safety Store there are departments on behavior support, crisis response, emotional/mental health supports, and person-centered planning for persons with dual diagnoses.*

Serving Persons with MR/DD Who Are Involved with State Criminal Justice Systems

by Michael Cheek

While the vast majority of people with life-long cognitive disabilities are law-abiding and productive citizens, a small percentage find themselves involved in the criminal or juvenile justice systems. Some states have begun programs aimed at assisting these individuals. Generally such programs focus on transitioning persons with mental retardation or a related developmental disability (MR/DD) out of the justice system and into education and/or community support systems that respond to their needs and behaviors in ways that reduce the likelihood of recidivism. These programs often operate side-by-side but separately from community crisis response programs. This article describes three such programs operating in three substantially different states.

The North Carolina Model

Recognizing that limited attention has been given to individuals with MR/DD within the justice system, the North Carolina Council on Developmental Disabilities (DD Council), the Division of Developmental Disabilities Services (DDS), and the North Carolina Center on Crime and Punishment have collaborated to assess the status of people with developmental disabilities in the criminal and juvenile justice systems. Based on the work of the Justice Task Force comprised of staff from MR/DD services, the DDS and justice professionals, a special report, entitled *In Pursuit of Justice: A Report on the Justice System's Response to People with Developmental Disabilities*, was developed to serve as a guide for creating new supports and services for persons with MR/DD involved with the criminal justice system. The task force found that the majority of persons with developmental disabilities in correctional facilities also were diagnosed with mental retardation, and, in

general, found that of the offenders with mental retardation studied:

- Each had a juvenile record;
- There was no mention in probation and parole reports that staff were aware of the offender's disability (i.e., identification of the disability did not occur until the offender entered the Division of Prisons); and
- Most were viewed as "willful and non-compliant" because of a lack of understanding in the corrections system of their disability. Consequently, they often failed to meet the conditions of probation and parole.

The task force also found that there was no communication among human service agencies including mental health, developmental disabilities, and substance abuse, and the criminal justice system. Furthermore, it noted that most mental health, developmental disabilities, and substance abuse professionals were often uncomfortable with offenders possibly due to a lack of knowledge and training about the criminal justice system.

Based on each of the service deficits identified, corrective recommendations were developed by the task force. Currently, the state DD services agency and the state DD Council are working on three separate initiatives based on the report recommendations. First, the DD Council funded a "bench and bar" training to county and local judges, prosecutors, public defender offices, and law enforcement officials. Held in Fall 1999, the training was intended to sensitize judicial and law enforcement officials to the needs of persons with developmental disabilities and educate them about the state's MR/DD service system. Secondly, the state DD services agency convened a statewide meeting composed of North Carolina Department of Correc-

tions social workers, MR/DD case managers, DD agency staff, and Department of Prisons staff. Topics included: a) definitions of services for transition protocol in and out the prison system; b) an overview of the MR/DD system and corrections system – including recent changes in sentencing structure; c) a discussion of victims services; d) case staffing issues; and e) the development of a sex offenders task force (anecdotal estimates by North Carolina officials indicate that as many as 30% of incarcerated persons with MR/DD who were convicted of a felony committed a sexual offense). Thirdly, the Justice Task Force plans on beginning a pilot project on community services for offenders with MR/DD in the eastern part of the state, based on Pennsylvania's Lancaster model.

The Oklahoma Plan

The State of Oklahoma has a statutory requirement that state courts refer offenders with MR/DD to the Oklahoma Department of Human Services. These laws are intended to divert people with cognitive disabilities, mental illness or substance abuse from the criminal justice system into treatment and/or support programs. The Developmental Disabilities Services Division (DDSD) has a cooperative agreement with the Department of Mental Health and Substance Abuse Services concerning the population diverted from the state court system. Under this agreement, offenders with cognitive disabilities, or a mental illness and substance abuse are referred to the Robert M. Greer Center, a state facility for persons with MR/DD and/or mental illness operated by DDSD. Since 1996 Oklahoma has also maintained a Habilitation Center in the Joseph Harp Correctional Facility. Begun with a funds from the Oklahoma Developmental Dis-

abilities Council and now operated by the state Department of Corrections (DOC), the center was established to provide services to offenders with cognitive disabilities that will “help each participant to function at his optimal level in a law abiding manner.” Referrals are made from DOC or by court order and are then reviewed by an interdisciplinary team responsible for developing an Individual Habilitation Plan (IHP).

Offenders who exhibit behavior dangerous to themselves or others, who have received maximum security status, or who are diagnosed with acute mental illness requiring inpatient treatment are excluded from eligibility. The program is intended to aid participants in improving adaptive skills in major life areas as identified in assessments. Offenders take part in community living skills, vocational and academic training, and work towards goals and objectives set out in an IHP that documents progress towards eventual graduation from the program. Upon completion of the program, the offender may receive services in another unit or another facility with regular contacts by center staff; find placement in a non-correctional program; or continue enrollment in the Harp Center. Annually, data is gathered to evaluate effectiveness based on achievement of goals and objectives by participant offenders, work performance of graduates (i.e., pay, performance evaluations, tenure) and return to a correctional facility.

The New York System

The State of New York has structured its correctional programs with the intent that persons with mental disabilities charged with crimes or convicted of crimes not be treated in the same manner as persons without disabilities based on the following findings: a) persons with MR/DD may not understand their rights; b) they have tendency to respond to questions in the manner they believe is expected of them; c) individuals with MR/DD may have difficulty communicating with their legal counsel; d) they

are frequently abused by fellow inmates; and e) there is a lack of appropriate diversion or alternative treatment programs for persons with MR/DD who are incarcerated. New York penal law and criminal procedure law codifies sanctions for those judged not responsible for their actions by reason of mental disability. Aimed at identifying individuals with mental illness and cognitive disabilities, these provisions are intended to divert them from further criminal processes, and ultimately provide care outside correctional settings for those who are not found criminally responsible for their actions.

In New York, following a clinical evaluation, if the court determines that the defendant is “incapacitated (one who as a result of mental disease or defect lacks capacity to understand the proceedings against him or to assist in his own defense),” he or she is committed “to the custody of the commissioner [of mental retardation and developmental disabilities or mental health] for care and treatment in an appropriate institution....” In the case of a misdemeanor and a finding of mental disability, criminal action is ceased with follow-along as appropriate. If the charge is a felony, however, the law requires greater consideration by the courts. The state code stipulates that the appropriate commissioner must “...designate an appropriate institution, operated by the department of mental hygiene in which the defendant is to be placed.”

New York has offenders with MR/DD in three corrections programs. The programs offer vocational, educational, and recreational training. Six months following release, offenders with MR/DD may participate in a community linkage program or receive community support services through the New York Office of Mental Retardation and Developmental Disabilities.

Nationwide Progress

These and other states continue to strive for better methods of: a) training and preparing justice, law enforcement, and health and human services personnel to assist persons with MR/DD involved with the justice system; b) identifying offenders with MR/DD; and c) targeting points of diversion for offenders with MR/DD from the standard adjudication track once in the court system. Meanwhile, Congress has passed the America’s Law Enforcement and Mental Health Project Act (S.1865). It amends the Omnibus Crime Control and Safe Streets Act of 1968, authorizing the attorney general to make grants to states, state and local courts, or units of local government for programs that involve: a) continuing judicial supervision, including periodic review, over offenders with mental illness, mental retardation, or co-occurring disorders who are charged with non-violent offenses; and b) the coordinated delivery of services, including specialized training of law enforcement and judicial personnel to identify and address the unique needs of offenders with mental illness or mental retardation. The programs include voluntary outpatient or inpatient mental health treatment that carries with it the possibility of dismissal of charges or reduced sentencing upon successful completion of treatment, centralized case management involving the consolidation of all cases of defendants with MR/DD or mental illness, and the coordination of all mental health treatment plans and social services, including life skills training. These funds will be blended with current state efforts to improve identification of and services for persons with MR/DD who become entangled in the justice system.

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Innovation in Colorado: The Pueblo DD/MH Consortium Diversionary Program

by Larry Velasco and Lamar Trant

It has been over 13 years since the Pueblo DD/MH Consortium was established as a volunteer network of agencies willing to work cooperatively with one another in an endeavor to provide effective quality services and supports to individuals with developmental disabilities and mental health needs who are also classified as offenders. The Consortium became a reality in the Spring of 1987 after Colorado Bluesky Enterprises Inc. (formerly known as Pueblo County

“hot potato” game. Any individual who had a dual diagnosis of DD/MI who was creating problems in the community belonged to the “other guys.” No one wanted to accept responsibility for assisting the DD/MI offender who challenged any service delivery system.

What was a “stone throwing” relationship in 1987 has evolved into a “mutual admiration society” which has been discovering creative means to assist some of the most difficult to serve persons in the community. The very simple goal of coming together on a monthly basis and listening to case presentations about challenging individuals has evolved to the cooperative creation of action plans for individuals which are communicated to the courts via the individual’s service coordinator. Consortium members review the individual’s case as presented by the person’s service coordinator, ask questions, and identify potential resources which may come from any of the participating agencies. No agency is asked to do something it is unable to do and no extraordinary measures are expected where resources are unavailable. Each agency representative knows what they can voluntarily commit to as a resource for any person’s plan. State agencies assist private non-profit agencies and vice versa, creatively utilizing resources to the maximum degree. Once the elements of the plan are solidified and verified by the service coordinator, it is provided to the judge either through discussion with the assistant district attorney or the public defender. Generally, both parties and the individual with developmental disabilities who has committed an offense agree upon the plan before submitting it to the judge in court. If there is disagreement, the assistant district attorney may still present the plan as developed and the public defender will object on whatever basis is relevant. The judge may ei-

ther accept the plan as written or may ask that the parties do additional work and return with possible changes to the plan. The judge insures that the defendant’s rights are not violated and that the community services are in place when the final sentence is made.

An important component of the Consortium’s efforts has involved training for the judges in Pueblo about people with developmental disabilities and their supports and services in this community. They have also learned about the willingness of the Pueblo human service professional community to work together to develop viable plans. These plans include mental health intervention as well as behavioral programs structured to insure an individual’s success in closely supervised well-managed services. The individual plans insure the court that each person will have little to no opportunity to re-offend against individuals in the community. The “diversion program” which has been developed by the Consortium is not a formal diversion program. It is tailor-made to fit the individual’s level of functioning and the community service agencies’ abilities to provide consequences to respond to each individual’s needs.

Recently, the Consortium hosted our bi-annual “Judges’ Dinner” where the judges listened to presentations by mental health and developmental disabilities professionals on the current status of the Consortium and its activities. Also attending this event were representatives from the police and sheriff’s departments, probation, and the public defender’s office. The judges were very positive and commended the Consortium members for providing such an effective diversion process for this target group. They further expressed their thanks because the rate of recidivism for these individuals has been remarkably low in comparison to the norm.

Previously, any individual who had a dual diagnosis of DD/MI who was creating problems in the community belonged to the “other guys.” No one wanted to accept full responsibility.

Board for Developmental Disabilities) received a visiting professor grant from the Colorado Developmental Disabilities Planning Council for the purpose of receiving consultation from an expert who worked successfully with individuals who had dual diagnoses of developmental disabilities and mental illness (DD/MI). Dr. Peter Holmes, from Eastern Michigan University, was the catalyst for bringing together frustrated professionals from the state mental health and developmental disabilities departments, private hospitals in Pueblo, the state hospital for persons with developmental disabilities, the county department of social services, and representatives from the local school districts. Prior to the grant, agencies played the

The Consortium has also recently developed Project A.S.S.I.S.T (Assault, Safety, and Social Intervention Systems Training). This project provides a voluntary, centralized identification and tracking system for individuals with developmental disabilities who are classified as offenders or those who may otherwise come to the attention of law enforcement officers or emergency psychiatric or medical personnel due to behavior which is a danger to self or others. Individuals with medical conditions such as seizures or uncontrolled diabetes, or problems with drug or alcohol abuse may also be included in the tracking system. A contact number is made available to police and sheriff dispatch personnel for immediately accessing critical information and understanding about individuals who may be “picked up” on the street by law enforcement personnel or who may be reported by program staff in need of police or sheriff assistance. Details of this process are shared with the criminal justice system through training sessions and the involvement of law enforcement personnel in Consortium meetings. This process further enhances the “system’s” ability to address the health, safety and well-being of all of the community’s citizens by maintaining a cooperative working relationship between the human service agencies and the criminal justice system. Several hundred Pueblo police officers and sheriffs officers will be trained at least once a year beginning in January and February 2001. Training sessions will also be held with the district attorneys, public defenders, and probation officers. Sessions have been provided to criminal justice officers during the past 13 years, however, this has not occurred on an annual basis and, consequently, many new law enforcement officers have not been trained in regards to special needs individuals.

Another form of training is being provided directly to persons with developmental disabilities through Safety First classes which are administered by the Arc of Pueblo, Colorado Bluesky Enterprises and several members of their

service agencies. These classes are taught by police officers and fire fighters and they provide individuals with developmental disabilities an opportunity to develop a supportive rapport with these public servants. The Safety First program has been funded by a grant from the Colorado Developmental Disabilities Planning Council.

Last year, Colorado Bluesky Enterprises’ offender program was renamed the RESULTS program (Resocialization through Understanding, Limits, Training and Support) in order to eliminate the stigma associated with the use of “offender.” A new residential RESULTS program for females who have come to the attention of the legal system has also been implemented. The need for this highly structured and supervised program became critical due to the increase in the number of females who have become difficult to serve in a more typical residential program. Currently there are three women served in this program. A RESULTS day program/work component has also been added for both females and males which primarily takes place on a seven-acre farm. The program provides a more isolated environment for these individuals to help eliminate undue attention to extreme challenging behavior and to insure public safety. These individuals have previously engaged in aggressive, run-away or sexually assaultive behavior in public settings, such as a college campus and a city parking garage while working on crews performing contractual work in the community. In addition to the work component of this program, individuals will also learn to be responsible for llamas and dogs raised on the farm. This is designed to provide an opportunity to learn compassion for another living being that is dependent on them for food, water, grooming and love.

One of the many individuals who has benefited from the RESULTS program is Carl.* He was served in the program for three years following several incidents of sexual assault and inappropriate sexual conduct. After three years of intensive programming and significant

progress, he earned the opportunity to live in a Host Home with a married couple who are both highly skilled in working with individuals with these types of problems. He continues to receive very close supervision and ongoing social skill training. Reflecting on his experience with the program, he says:

Before I was in the RESULTS program I lived in several Host Homes and worked at McDonalds. I had to move to the RESULTS program because I was lying, being aggressive, ran away, and had problems with my sexual behavior. When I was younger, I was living in Denver in a big group home, and I was being aggressive at home and at the high school. Then I moved to the RESULTS home and I was on a program earning points and moving to higher levels. The staff helped me move on and do more things in life. Now I am on a work crew at a community college. I also help out at church putting the food in boxes of Care and Share, and I help out my neighbor and family members. Most of all what I need to work on is my sexual behavior, my aggression, and not lying. I am also working on asking for my needs and wants. Now I go to the Appropriate Social and Sexual Expression Therapy (ASSET) group, and my team helps me make the right choices to help me have joy in life.

In summary, the Pueblo DD/MH Consortium continues to be an important catalyst for many innovations that have demonstrated positive effects for individuals with developmental disabilities who are also offenders. We look forward to more successes, collaboration, and creativity in this remarkable volunteer community network.

*Pseudonym

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[Smull, continued from page 1]

at how someone “wants to live” necessarily takes a “Maslowian” back seat to having shelter. But the temporary shelter often becomes a permanent place to live, at least until that person informs us with their behavior that they can no longer tolerate the situation into which they were “placed.” Those who need immediate shelter (with insufficient time for planning) are telling us what is lacking in our system; however, they are only seen as individual “problems” that need a quick solution. There has to be a quick solution because the officials need to move on to the next crisis. In a crisis culture there is no time for thought about real solutions, and the cycle of having today’s temporary solutions adding to tomorrow’s crises is maintained.

Learning from Crises

The officials who are asked to make the crisis “placements” have the opportunity to break the cycle of crisis. They may have to help the person move “now”, but they don’t have to wait until the quick solution turns into the next crisis. They can require that evaluations be done to learn how the person wants to live and look for alternative frames of understanding the person’s needs, preferences, and behaviors. The goal should be a better balance. Balance implies that the person gets more of what is important to him or her as a unique individual, and that issues of health or safety are effectively addressed within the context of how the person wants to live. One way to look at this balance is to ask those involved the following questions:

- Do any of these alternate ways of understanding the individual’s issues and behavior suggest positive actions that could result in a better balance?
 - If these alternative ways of understanding are acted upon, how will people know if the changes work?
- Just as learning to analyze behavior using a behavioral frame is a skill, so is learning to listen to how a person wants to live. For those who practice “positive behavioral supports” it is a clearly overlapping skill, but it is sufficiently different to warrant separate training. It is a way of listening that uses a somewhat different framework, and applying that framework requires practice. It is about listening carefully and intently. This intense kind of listening has been called *active listening* (Farston, 1996), and it has been described as a “mindful” activity (Langer, 1989). Too often there is an assumption that professionals already know how to do this. There is an expectation that a professional can go to a day-long workshop providing an overview of three kinds of person-centered planning training, look at a couple of sample “person-centered” plans, and then go forth and effectively learn how other people want to live. My experience and that of my colleagues is that it is a rare person who can pick up this new skill without extensive structured practice. It is even more challenging to apply this skill when there is a crisis. In a crisis, there is no time for reflection, for puzzling something through. In a crisis there is pressure for a quick solution. Applying a skill that is still being developed in a crisis setting is a recipe for distortion and disaster. Only those already skilled can effectively respond.
- When officials engage in an analysis of multiple crises they often identify deficits in system capacity. For example, they often see a need for training in the frames of understanding that we have labeled “person-centered planning.” Or they may find a need for mental health professionals who are able to effectively evaluate and treat people with cognitive impairments. Quite often a need is identified for support services that permit people to have a place they call home and opportunities to contribute to communities. The best officials see the challenges of those in crisis as symptoms of system deficits. These “best” officials also see development of new capacity as one of their core responsibilities.
- For those whose crisis arises because they can no longer live with their families, an important opportunity has been lost. In such situations, the system typically waits until people are in crisis before offering support, and then it is too late. As a result people move out of the family home and the system begins all over again to try to build community for people who have lost community due to its delayed response. The time to learn what is important to the person is while they are living with their family. Many parents are happy to develop plans with their sons and daughters and to begin to act on what is being learned while they are active and able. Parents who do not have the energy to take the lead in planning still have extremely valuable information about the person. When we wait until the parents are disabled, deceased or defeated, we have lost the information and the opportunity for building community that could have occurred.

Using Person-Centered Planning

There are ways pre-crisis planning can occur other than the funding of a large number of new service coordinators. Among the alternatives is to recruit parents who are interested in acquiring the skills needed to help other parents plan, and then to pay them to help other parents develop and implement plans. Self-advocates are another neglected resource. Increasing numbers of self-advocates are being helped to develop plans on themselves. Many of them are interested, capable, and willing to assist others in developing their own plans. Parents and self-advocates may not always have the specialized clinical knowledge needed for some people to be healthy or safe, but they make excellent partners as they almost always know

how to see things through the lens of having a better life. They will almost always push for a better balance.

If new conceptual frameworks are to be broadly applied, there needs to be extensive training and support in learning how people want to live and in addressing issues of health and safety in the context of what is important to the person. But there also needs to be recognition that different conceptual frameworks rest on different sets of assumptions. In the old conceptual framework, an often-unstated assumption was that professionals knew what was best and should make decisions for people. When this assumption is explicitly discussed it is rationalized with concepts of generalized incompetence, such as mental age (e.g. "He has a mental age of four, so of course we are going to decide what is best"). In saying that we know better, we ignore the fact that everyone has preferences regardless of cognitive capacity, and we ignore the complexity of intelligence (Gardner, 1993). In a rush to an over-simplified view of self-determination, we hear the equally perverse statement: "I was in charge yesterday but because we now believe in self-determination today you are in charge." The preferences that we have today are largely based on our prior life experiences. Much of what we want depends on what we have tried; an absence of opportunities narrows preferences. For all of us choice has boundaries and control is shared; within this "new" conceptual framework what is true for the typical person is also true for those who use disability services.

In sharing control, the goal is to help the person have as much positive control as is possible. The role of the professionals and members of the person's support team is to look for the best balance between what the person wants, what others want for the person, issues of health and safety, and the use of limited public resources. This is an ever-shifting balance and one that frequently has tensions between competing interests and perceptions. It does require new skills. Some of these have been dis-

cussed but there are others (e.g., the skill of negotiation) that are needed. The experiences of those who are moving down this path also indicates that acting on these concepts and using these skills requires extensive changes in policies, practices, and organizational culture. However difficult all of these efforts may seem, they are easier to accomplish and far more rewarding than seeking compliance from people who do not like where, how, and/or with whom they are living.

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[Lakin, continued from page 3]

The *Olmstead* decision, the advancing state-of-the-art in providing community services, and the accomplishments of "institution-free" states challenge all states to develop and sustain effective, community-based behavior support and crisis response services. For many states this will be difficult because a) they have focused their behavior support resources and personnel in institutions; b) they and their private contractors have often come to view these institutions as the "appropriate" places for people who present behavioral challenges; c) state and private community agencies have often developed a mutually reinforced tendency of accepting that institutions are the place to send people with challenging behavior when they are uncomfortably difficult for community agencies to serve; and d) as a result of limited involvement among states and localities in responding to highly challenging and crisis behavior in the community, many have limited technical and experiential capacity to do so.

There have been, however, a number of states and local agencies that have re-

sponded to these same challenges in developing community behavior support and crisis response programs. These lessons learned in their development include the importance of acknowledging and responding to mental health conditions among persons with MR/DD; valuing and incorporating professionals with different psychological, medical and social perspectives; attending carefully and responding seriously to what people are saying through their behavior; committing to people and their right to live in the community; and building the capacity within community organizations and families to reduce and respond to behavioral episodes without outside intervention. The experience of these states and agencies offers substantial hope that with appropriate community support all persons with intellectual and developmental disabilities, including those with serious behavioral and psychiatric conditions, can be and can remain residents of homes and neighborhoods in typical communities.

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In This Issue...

- **A Crisis is Not an Excuse**
- **Meeting the Challenge: Crisis Services in the Community**
- **Community for All: Experiences in Behavior Support and Crisis Response**
- **Functional Assessment: Responding to Challenging Behavior**
- **Training and Technical Assistance Strategies for Behavior Support and Crisis Response**
- **Profiles from Vermont, California, Colorado, Massachusetts, Minnesota, North Carolina, New York, and Oklahoma**
- **Resources and More . . .**

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